



Utah *Dialogue* on Ovarian Cancer

Salt Lake City

MAY 2007

Overview of the *Dialogue for Action*

Dialogue for Action, a signature program of the Prevent Cancer Foundation (formerly the Cancer Research and Prevention Foundation), offers a unique opportunity for a state to develop or enhance a working consensus for cancer prevention and early detection.

The *Dialogue* process brings together a diverse group of individuals and organizations united by their dedication to decrease morbidity and mortality from cancer through prevention and early detection. By bringing together groups with like-minded missions and diverse constituencies, the *Dialogue* process helps a state to implement objectives in its comprehensive cancer control plan. By strengthening cancer-related collaborations and identifying the steps that can be taken for positive change, the *Dialogue* process can help state-level cancer efforts yield positive

effects on people's lives.

The *Dialogue for Action* began in 2000 as an annual national conference, to focus national efforts on increasing colorectal cancer screening. After Utahns involved in comprehensive cancer activities attended the national *Dialogue*, they worked with the Foundation to bring the *Dialogue* process to Utah, to accomplish the same aim for the state. In 2002, Utah convened the first-ever state-level *Dialogue for Action* to increase colorectal cancer screening. This conference mobilized people, organizations and resources in Utah, and its outcome was a successful proposal to the Centers for Disease Control and Prevention to fund a multi-year, multi-media project to increase public awareness of colorectal cancer screening in the state.

Based on the successful outcome of that *Dialogue*, Utahns recently approached the Foundation about

working together to develop a *Dialogue* on ovarian cancer that would enhance state-level activities in that cancer arena. Planners wanted to find ways to better serve women with ovarian cancer diagnoses, even in the absence of effective screening.

In 2007, Utah convened the first-ever state-level *Dialogue* on ovarian cancer. "Ovarian Cancer in Utah: Improving Outcomes for Women" took place on May 5, 2007, at the Marriott University Park Hotel in Salt Lake City, with 35 attending. Participants included primary-care physicians, general surgeons, obstetrician/gynecologists, gynecologic oncologists, nurses, program administrators, advocates, health educators and researchers. This report provides an overview of the Utah Ovarian Cancer *Dialogue*, highlighting its goals, accomplishments and next steps.

Before the Utah *Dialogue* on Ovarian Cancer

The ball started rolling for a Utah *Dialogue* on ovarian cancer when an ovarian cancer survivor and a gynecologic oncologist, members of the Utah Cancer Action Network (UCAN), wanted to change the general perception of ovarian cancer as the "silent killer." They educated

UCAN members about the symptoms of ovarian cancer – that earlier detection is possible. This led to the start of the Ovarian Cancer Committee in 2005. Ovarian cancer has been a UCAN priority for the past two years, and it is part of the state comprehensive cancer control plan.

Key staff of the cancer control program of the Utah Department of Health and members of the Ovarian Cancer Committee saw the *Dialogue* process as a means of bringing ovarian cancer stakeholders in the state together to lay the foundation for greater collaborative action.

Utah Planning Committee

Maritza Arce-Larreta, ANPR
UCCP-UDOH
Philip Brown
Breast and Cervical Cancer
Task Force
Bronwen Calver
UCCP-UDOH
Janet Heins
Huntsman Cancer Inst.
Whitney Johnson
UCCP-UDOH
Lynne Nilson
UCCP-UDOH
Kathryn Rowley, RT
UCCP-UDOH
Antoinette Stroup, PhD
Utah Cancer Registry
Karen Zempolich, MD
U of U School of Medicine

Conference Speakers

David Sundwall, MD
UDOH
Karen Zempolich, MD
Huntsman Cancer Inst.
Saundra Buys, MD
Huntsman Cancer Inst.
Stephani Hall
Ovarian Cancer Survivor
Mary Scroggins, MA
In My Sister's Care
Kasia Blaszczak
Ovarian Cancer Survivor
Antoinette Stroup, PhD
Utah Cancer Registry
Kathryn Rowley, RT
UDOH
Nicole Cozier, MBA, MS
Prevent Cancer Consult.

Conference Facilitators

Kalynn Fillion
UDOH
Teresa Garrett
UDOH
Lynne Nilson
UDOH

Conference Recorders

Philip Brown
UDOH
Heather Bush
UDOH
Whitney Johnson
UDOH

UCAN Ovarian Cancer Comm.

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**Before the Dialogue (cont.)**

A planning committee was then organized (see the list of members) to develop the *Dialogue* with Foundation staff. In Spring 2007, the committee envisioned a day of state-of-the-art presentations and invigorating discussion that would result in recommendations for developing a plan of action to improve how Utah addressed ovarian cancer.

Working from the ovarian

cancer objectives in the Utah plan, the planning committee selected these objectives for the *Dialogue*:

- ◊ To develop recommendations about how to work together to accomplish earlier diagnosis of ovarian cancer
- ◊ To develop recommendations about how to offer optimal treatment for ovarian cancer in Utah

With these objectives in mind, planning committee members and Foundation staff went to work. They defined the target audience and identified contact lists, drafted an agenda, identified national and state speakers, developed conversation topics, chose resources to distribute as part of the welcome packet, and brainstormed possible outcomes to the *Dialogue* conference.

The Day of the Utah Dialogue

At the start of the day, Kathryn Rowley, RT, and David Sundwall, MD, of the Utah Department of Health, welcomed the participants and stressed the importance of the day's work for women with ovarian cancer in Utah. During the morning, the *Dialogue* set the stage with distinguished speakers.

Antoinette Stroup, PhD, Deputy Director of the Utah Cancer Registry, presented statistical data on ovarian cancer in Utah. Dr. Stroup discussed incidence and mortality rates, staging distributions, survival by stage, trends in physician specialty, and geographic trends. She demonstrated that, over the past eleven years, there has been no substantial decrease in the incidence and mortality rates of women diagnosed with ovarian cancer in Utah.

Saundra Buys, MD, an oncologist at the Huntsman Cancer Institute, gave a talk on "Ovarian Cancer Screen-

ing: Update from the PLCO Cancer Screening Trial," a large randomized study of screening for prostate, lung, colorectal and ovarian cancer. She described the "intuitively appealing" nature of screening and the complex set of factors needed to make it effective. She explained that screening for ovarian cancer was still on the drawing board. Her reasons included these:

- The effect of screening on mortality has yet to be evaluated and will need longer follow-up.
- A reliable screening tool has yet to be identified.
- Current data are not sufficient to change the US Preventive Services Task Force recommendation against routine screening.

Karen Zempolich, MD, a gynecologic oncologist at the Huntsman Cancer Institute, discussed "Optimal Treatment of Ovarian Cancer." Among the topics

that she covered were these: risk factors, diagnosis, primary management (with the initial surgery including thorough surgical staging and aggressive tumor resection) and chemotherapy (including the potential for increased survival from intraperitoneal chemotherapy). She also presented data showing that patients were less likely to have reoperation if the initial surgery was done in a hospital with a high or intermediate volume of ovarian cases; by a gynecologic oncologist compared to a general surgeon; by a general obstetrician/gynecologist compared to a general surgeon; and by a high-volume surgeon (more than 10 ovarian cancer cases/year). Dr. Zempolich concluded her talk by saying that it will take patients, primary providers, gynecologic oncologists and medical oncologists all working together to ensure optimal treatment for patients.



The Day of the *Dialogue* (cont.)

Mary J. Scroggins, MA, a women's health advocate and ovarian cancer survivor with *In My Sister's Care*, spoke about the importance of partnerships among patients, survivors, health care providers and scientists to ensure optimal care and improve outcomes. She shared examples of successful partnerships and programs, (such as the "Survivors Teaching Students" program where ovarian cancer survivors share their experiences with medical students) and provided resources for help in creating future partnerships in Utah.

Kasia Blaszcak, an ovarian cancer survivor, shared her story with the participants. She attributed her survival to paying attention to her symptoms and receiving specialized care from a gynecologic oncologist. Ms. Blaszcak stressed the

importance of knowing the symptoms of ovarian cancer for earlier detection, and the need for access to specialized treatment to increase survival. (Stephani Hall, also a survivor, was not able to attend the conference)

The second half of the *Dialogue* was devoted to three concurrent conversations, each with a diversity of participants. Each group was assigned one of these topics:

1. What will it take to enhance relationships and collaboration among Utah's varied providers so that outcomes are improved for women with ovarian cancer?
2. How can providers, survivors, and advocates form partnerships to improve outcomes for women with ovarian cancer in Utah?
3. What messages should provider education and public awareness campaigns convey regarding

ovarian cancer in Utah, and how should those messages be disseminated?

Group participants discussed possible answers to their assigned questions and possible implementation challenges. They then generated suggestions for what Utah should do to improve the picture of ovarian cancer in the state. After finishing their conversations, participants reconvened as a whole for conversation report-outs.

Concluding the *Dialogue*, Ms. Rowley thanked everyone for their contributions to the day. She explained that conference organizers would turn the groups' suggestions for action into an online survey and ask that participants prioritize the suggestions. The results would then be used to set priorities for moving Utah forward in ovarian cancer.

Conference Attendees

Maritza Arce-Larreta, ANPR
UDOH
Tom Belnap
Intermountain Healthcare
Adam Blaszcak, PhD
Cancer Researcher
Cindy Cannon, MD
Theresa Coombs, RN
Office of Dr. Joseph D. Te
K Didion, RN
Office of Dr. Joseph D. Te
Mark Dodson, MD
University of Utah
Randy Hansen, MD
Intermtn. Med. Group
Janet Heins
Huntsman Cancer Inst.
Aziza Keval, MD
Exodus Healthcare
Network
Ladene Larsen, RN
UDOH
Robin Mainwaring, MD
Gynecology Affiliates
Diane Miller, RN
Tri-Cnty Local Health Dept
Sean Patrick
HERA
David Richards, MD
Intermtn. Med. Group
Kathryn Rowley, RT
UDOH
Michael Siler
American Cancer Society
Pat Soisson, MD
Joan Van Atta, NP
Huntsman Cancer Inst.
Theresa Werner, MD
Huntsman Cancer Inst.
Laura Zauderer
CDC

Keypad Findings

At the start and end of the *Dialogue* conference, participants responded to questions using individual wireless keypads.

Some key findings from the morning:

Fifty-eight percent of participants thought that women in Utah were "not informed at all" about ovarian cancer, and 63% thought that physicians were "somewhat informed."

Ninety-two percent of participants thought that Utah is not currently doing all it can to lower the mortality rate for ovarian cancer.

Some key findings from the afternoon:

Knowledge of key facts was strengthened. In the morning, for example, 72% correctly identified the statement "Ovarian cancer has no symptoms in its earlier stages" as false; in the afternoon, the figure rose to 89%.

To the question, "Should we organize another Ovarian Cancer *Dialogue for Action* conference in Utah?," 91% said yes, with more than half choosing "once a year" and the rest choosing "once every 2 years."

Seventy-five percent expressed strong agreement with the statement, "Overall, this conference provided useful information to me," and 21% expressed agreement.

Special thanks to:

Kathryn Rowley, RT, of Utah Cancer Control Program, UDOH

Karen Zempolich, MD, of the Huntsman Cancer Institute and Chair of UCAN Ovarian Cancer Committee

Funding

The Ovarian Cancer *Dialogue for Action* was funded through a grant from the Centers for Disease Control and Prevention, Comprehensive Cancer Control.

Evaluation Quotables:

Q: "What will you do differently as a result of this conference?"

A: Selected Answers

- "Be a better educator to my clients – know how to help them find the appropriate provider for their needs."
- "Provide education to my patients re: ovarian cancer signs and symptoms."
- "I will work harder to build collaborations with other health care providers and educate."

To improve diagnosis at earlier stages, know these symptoms:

- Abdominal pain, swelling, or bloating
- Gastrointestinal disturbances
- Urinary problems
- Fatigue/Malaise
- Change in appetite
- Frequent symptomatic episodes (12+ times per month) and symptoms persist for 3+ months

— From "Ovarian Cancer in Utah: A Factsheet for Medical Professionals," May 2007

Staging and Survival

Nearly 1/3 of Utah women with ovarian cancer are not diagnosed until Stage IV, when the cancer has metastasized, and 39% are never staged.

—From "Ovarian Cancer in Utah," April 2007

**Conference Evaluation**

The objective of the conference was to 1) Discuss and analyze issues and optimal treatment for ovarian cancer in Utah and 2) Develop a plan for action to address ovarian cancer in Utah. Participants were surveyed and asked if the conference objectives had been met. Sixty-five percent of respondents indicated that the conference/summit met the first objective, and 60% indicated that the second objective had been met.

Participants were surveyed on their satisfaction with the

concurrent conversations, based on their participation in the conversations and summary of each conversation presented at the end of the day. Of Conversation #1, "What will it take to enhance relationships and collaboration among Utah's varied providers so that outcomes are improved for women with ovarian cancer?" 100% of respondents indicated that they were satisfied or very satisfied. Conversation #2, "How can providers, survivors, and advocates form partnerships to improve outcomes for women with ovarian cancer?" resulted in 59% of

respondents who were "very satisfied," and 35% who were "satisfied." Of Conversation #3, "What messages should provider education and public awareness campaigns convey regarding ovarian cancer in Utah and how should those messages be disseminated?" 72% of respondents were "very satisfied" and 22% indicated they were "satisfied." Finally, 94% of respondents were satisfied with the conversation and facilitator report-outs; 6% indicated a neutral response.

After the Dialogue: The Survey

Following the *Dialogue*, participants completed an online survey based on recommendations generated by the concurrent conversations at the conference. Participants were asked to select top priorities for action and key messages for future provider and public awareness campaigns.

The respondents (N = 19) were first asked to rate each of 8 items based on their priorities. They recorded their ratings for each item as (1) high, (2) medium or (3) low priority.

The following list reflects their responses to the eight items. It ranks their average ratings in descending order.

1. "Identify breakdowns in collaboration"
2. "Networking/building relationships among providers"

3. (Tied) "Continued group training that includes CEUs/CMEs" and "Provide education for patients"
4. "Needs assessment of different communities"
5. "Education packet for providers"
6. "Web/PowerPoint training that includes CEUs/CMEs"
7. "One-on-one training using doctors, nurses, and/or advocates"

Priorities for respondents were also gauged by another question: "If you could pursue only one of the items below, which one would you choose?" Here is the descending order of frequency of their responses:

- "Networking/building relationships among providers" was the top choice of almost 32%.
- "Identify breakdowns in collaboration" was tied

with "One-on-one training using doctors, nurses, and/or advocates" at just over 21%.

- "Continued group training that includes CEUs/CMEs" was tied with "Web/PowerPoint training that includes CEUs/CMEs" at a little more than 10%.
- "Provide education for patients" was chosen by a little more than 5%.
- No respondents chose "Matrix for each specialist," "Education packet for providers" or "Needs assessment of different communities."

Respondents (N = 19) were also asked to rate possible key public messages about ovarian cancer. Their first task was to rate each of five items as (1) high, (2) medium or (3) low priority.



The Survey (cont.)

The following list reflects their responses to the five items. It ranks their average ratings in descending order.

1. "Educate public on signs and symptoms, specifically they are not vague and are persistent for at least 2 to 4 weeks" was tied with "Educate doctors before public" for the top spot.
2. "Educate public that Paps only screen for cervical cancer, all women are at risk regardless of age or race, understand risk factors, symptoms even in early state, and appropriate specialty care is critical."
3. "Patients should ask 3 ques-

tions: How do I prevent ovarian cancer? Should I be screened? If my health care provider says I have ovarian cancer, whom should I see?"

4. "Create hopeful messages."

Finally, respondents (N = 19) were asked, "If you could pursue only one of the Key Public Messages, which one would you choose?" Here is the descending order of their responses:

- Almost 32% chose "Educate doctors before the public."
- The next choice was "Educate public on signs and symptoms, specifically they are not vague and are

persistent for at least 2 to 4 weeks" (a little more than 26%).

- Tied for third place at about 21% was "Educate public that Paps only screen for cervical cancer, all women are at risk regardless of age or race, understand risk factors, symptoms even in early state, and appropriate specialty care is critical" and "Patients should ask 3 questions: How do I prevent ovarian cancer? Should I be screened? If my health care provider says I have ovarian cancer, whom should I see?"
- No one chose "Create hopeful messages."

Post Dialogue Activities

- Since the *Dialogue*, Utah Cancer Action Network (UCAN), the Utah Cancer Registry and the Utah Department of Health created "Ovarian Cancer in Utah: A Fact Sheet for Health Care Professionals" which provides information on the state of ovarian cancer in Utah, staging and survival, and the signs and symptoms of ovarian cancer. The fact sheet has already been sent to 2,500 physicians (surgeons, ob/gyns, primary care physicians, and gastroenterologists).
- The Utah Department of Health is completing a com-

prehensive women's health survey. The goal is to collect up-to-date information from 1,000 women on individual and family health histories and knowledge of women's health issues, including ovarian cancer.

- Contingent upon funding, the Utah Department of Health plans to contract with the Utah Cancer Registry to conduct two state-wide surveys to further assess the state of ovarian cancer in Utah. One survey will collect information on the knowledge and practices of health care provid-

ers when caring for patients who may present with symptoms of ovarian cancer and those who have been diagnosed with ovarian cancer. The second survey will collect information on the needs of the general public for a public awareness campaign.

- Partnering with the Utah Medical Association, the Utah Department of Health plans an ovarian cancer educational opportunity for health care providers in 2008 (also contingent upon funding).

Ovarian Cancer in Utah

- ♦ The average annual incidence rate for all women is 13.3 per 100,000.
 - ♦ The average annual incidence rate for women 55+ is 43.2 per 100,000.
 - ♦ From 1994 to 2003, the incidence of stage IV disease greatly decreased from 7.7 to 2.9 per 100,000. At the same time, the incidence of stage III disease increased from 0.4 to 3.9 per 100,000.
- From "Ovarian Cancer in Utah," April 2007

For further information about the Utah *Dialogue*, contact Bronwen Calver at bcalver@utah.gov.

For further information about the *Dialogue for Action* process, contact Sara Barrett at Sara.Barrett@preventcancer.org.

Prevent Cancer Foundation, formerly known as the Cancer Research and Prevention Foundation, is a national nonprofit health foundation whose mission is the prevention and early detection of cancer through research, education and community outreach.

Prevent Cancer staff can work with key stakeholders in a state to plan and convene a *Dialogue for Action*, designed to help implement objectives in the state's comprehensive cancer control plan. The *Dialogue* process strengthens existing partnerships and forges new ones, essential to accomplishing the aims of comprehensive cancer control planning.

Prevent Cancer Staff

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Utah Comprehensive Cancer Control Plan: Ovarian Cancer

Goal: Promote, increase, and optimize the appropriate utilization of high-quality ovarian cancer screening and follow-up services.

Objective: Increase the availability of education and awareness tools to aid in the identification of early stage ovarian cancer.

